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ABSTRACT

This paper reviews the research on how siblings respond to another sibling who has survived childhood cancer. The paper examines the siblings' ability to cope, adjust, and adapt to this stressor. Relevant interventions are also discussed. The research indicates that although siblings may experience heightened emotional and behavioral problems, overall their psychological adjustment is adequate and not altogether different from siblings in healthy families. The two strongest predictor variables appear to be the compound variable gender/age and the presence of problems existing before diagnosis. The siblings' level of maturity and ability to overcome stressors contributed to a healthy adjustment. When the siblings' level of ability to adapt is considered, those who are categorized as dysfunctional have more difficulty than siblings classified as resilient. Finally, interventions that promote family cohesiveness, adaptability, and open communication facilitated healthy coping, adapting, and adjustment. (Contains 46 references.) (Author/GCP)

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SIBLINGS' RESPONSE TO A SURVIVOR OF CHILDHOOD CANCER: A REVIEW OF THE LITERATURE ON WHAT LEADS TO HEALTHY ADJUSTMENT OR MALADJUSTMENT

A Doctoral Research Paper

Presented to

the Faculty of the Rosemead School of Psychology

Biola University

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Psychology

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by

Todd Lee Hamilton

December, 1998

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A REVIEW OF THE LITERATURE ON WHAT LEADS TO

HEALTHY ADJUSTMENT OR MALADJUSTMENT

by

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This paper reviews the research on how siblings respond to another sibling who has survived childhood cancer. The paper will examine the siblings' ability to cope, adjust, and adapt to this stressor. Relevant interventions will also be discussed. Generally, the research indicated that, although siblings may experience heightened emotional and behavioral problems, overall their psychosocial adjustment is adequate and not altogether different from siblings in healthy families. The two strongest predictor variables appear to be the compound variable gender/age and the presence of problems existing before diagnosis. The siblings' level of maturity and ability to overcome stressors contributed to a healthy adjustment. When the siblings' level of ability to adapt is considered, those who are categorized as dysfunctional have more difficulty than siblings classified as resilient. Finally, interventions that promote family cohesiveness, adaptability, and open communication facilitated healthy coping, adapting, and adjustment.

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This doctoral paper is dedicated to two people. It is dedicated to my father, Don Hamilton; through his hard work and dedication he allowed me to pursue my educational dreams. And it is dedicated to my wife, Tricia, with all my love. Words can not express my thankfulness to her for keeping me afloat; I wish to thank her for all of her prayers, support, patience, and love.

SIBLINGS' RESPONSE TO A SURVIVOR OF CHILDHOOD CANCER: A REVIEW OF THE LITERATURE ON WHAT LEADS TO HEALTHY ADJUSTMENT OR MALADJUSTMENT

Introduction

A diagnosis of childhood cancer is a catastrophic crisis that poses significant challenges to the stability and adaptive functioning of the entire family system. Following diagnosis, parents are faced with the difficult task of helping the ill child and siblings cope with the physical and emotional stressors of the medical treatments and the ambiguity associated with the illness; such stressors can include the side effects of treatment, psychosocial stressors, and adjustment to the possible survival of the child. Beyond the disease itself, the family also must learn to adapt to non-illness-related events of everyday life that pose additional stress on the family system. Each year approximately 8,000 children, from the age of 1 month to 18 years old, are diagnosed with cancer in the United States (Cook, 1996).

Over the last decade, medical treatments for cancer have improved dramatically and survival rates have substantially increased. Five-year survival rates vary considerably depending on the kind of the cancer. Overall, 68% of the children diagnosed with some form of cancer are still living 5 years after diagnosis (Cook, 1996). With an average age of onset of 5 years and treatment lasting 1 to 3 years, childhood

cancer affects the family system during the early child-rearing years, resulting in a population of survivors and siblings who are still young children (Kazak, Christakis, Alderfer, & Coiro 1994). Although children may recall little of the cancer experience, the long-term memory of the child's illness and its legacy in the family is likely to persist. Because cancer and its treatment affect not only the child but also other family members, the quality of adjustment to the ill child's survival should include the long-term effects on the siblings, parents, and the family system as well. In addition, having a child with cancer is recognized as one of the most distressing and stressful experiences a family may encounter, and the psychological implications for the family's surviving a life-threatening illness are not yet well understood (Kazak & Meadows, 1989). The short-term emotional and psychological effects of the diagnosis of cancer in a child are obvious and severe, with the diagnosis also having an immediate and often potentially devastating impact on the entire family system. The long-term emotional and psychological effects are less clear; they seem to be more subtle, yet they apparently continue even when the child survives.

Unfortunately, most research about childhood cancer has focused on the ill child's ability to cope, adapt, and adjust to the illness, resulting in insufficient research concerning family members' ability to cope, adapt, and adjust to the child's illness (Lewis, Hammond, & Woods, 1993). More recently, however, the healthy siblings' and parents' ability to adapt to and cope with the stress of illness in the family has been the subject of numerous investigations. Unfortunately, findings have been remarkably inconsistent. Some investigations have found considerable incidence of maladjustment, whereas others have found little or no effect. Findings have also included suggestions

that the experience of having a sibling with cancer may positively influence the healthy siblings' psychological development and ability to cope and adapt.

The research on children with cancer has emphasized several characteristics that assist the family members' ability to cope, adapt, and adjust to the treatment and survival of the ill child. In particular, Kazak and Meadows (1989) found that the quality of the marital and sibling relationships and having adequate social support were strongly associated with the family's ability to cope, adapt, and adjust positively. In addition, these researchers found that if every day functioning of the family was not significantly disrupted, this also contributed to a more healthy adjustment. Using general outcome measures, the research primarily indicated that long-term survivors of childhood cancer and their families experience adequate overall psychosocial adjustment and are not plagued by continued problems or maladjustment to the cancer experience (Campell, 1993; Kazak, Christakis, Alderfer, & Coiro, 1994). However, research findings by Hamlett, Pelligrini, and Katz (1992) were consistent with the finding that chronic childhood illnesses, including cancer, are chronic stressors that may affect normal childhood development as well the balance of relationships within the family system.

In summary, more than 67% of the children diagnosed with cancer survive longer than 5 years. The research on the siblings' ability to cope, adapt, and adjust to the survival of their ill sibling is beginning to shed light on the impact this stressor has on the family system. However, the research is inconclusive regarding the nature of the cancer experience for the healthy siblings and indicates a wide variety of outcomes. For some siblings, the cancer experience may be very challenging and the ability to cope, adapt, and adjust may be significantly hampered. For other siblings, there may be little or no

effect. And in still other siblings, there may be many positive influences on their psychosocial adjustment and ability to cope, adjust, and adapt to the many challenges that they may face in the future. Although living with a sibling who had cancer can be agonizing for the healthy siblings, their overall psychological adjustment is commensurate with siblings who did not have a sibling with cancer.

In this paper, the literature on siblings' ability to cope, adjust, and adapt to a childhood survivor of cancer in the family will be reviewed. The purpose of this review is to further the knowledge and research in the area of the long-term effects on the healthy siblings' functioning as it pertains to their ability to cope, adjust, and adapt to a sibling surviving childhood cancer. Furthermore, effective interventions for enhancing the siblings' ability to cope, adjust, and adapt in a healthy manner will be reviewed. It is hypothesized that if researchers can begin to understand the impact of cancer survival on siblings and delineate which factors may enhance risk for maladjustment, more effective coping, adjusting, and adapting techniques for siblings may be found. Finally, this research would benefit those mental health professionals who provide services to siblings to aid in their ability to cope, adjust, and adapt to living with a survivor of childhood cancer.

There is a large body of psychological research concerning questions related to the sequelae of the treatments used to cure childhood cancer, the psychological as well as neuropsychological effects of these treatments, and the manner in which the child with cancer perceives, copes with, and adapts to this stressor. Although the findings in this area are important, the focus on the individual provides little understanding of the relationship between the ill child and the healthy siblings. Therefore, this paper will not

include the literature pertaining to the child with the cancer due to the limited space, the scope of this paper, and the fact that it is covered elsewhere in the psychological literature.

Methodological Considerations

The increased survival rate for childhood cancer has led to a growing number of empirical research studies concerning the siblings' ability to cope, adjust, and adapt to the situation. However, given the limited number of children being diagnosed annually with cancer, compounded by relatively small numbers of children diagnosed in a given geographical area, methodologically sound studies may be precluded. Most comprehensive childhood cancer centers treat small numbers of children with numerous diagnoses; hence, samples adequate for research within a specific disease or age range are generally not available, a factor which may limit the specificity and generalizability of the findings. Drotar and Crawford (1985) and Drotar (1994, 1997) have written extensively on the assessment of the complexities of sibling and parent adaptation to chronic childhood illness and the major methodological shortcomings. The most common problem in studying the psychosocial aspects of childhood cancer on families, particularly siblings, is measuring the specific impact of the cancer experience. Existing standardized instruments allow for reliable judgments, but they are not well suited to the problem under study in childhood cancer (Rait et al., 1992; Sahler et al., 1994; Van Dongen-Melman, Pruyn, De-Groot, & Koot, 1995). These instruments are not preferable because they were developed more specifically to differentiate between psychopathology

and "normalcy," not resilience or vulnerability. Keeping these limitations in mind, the following are some methodological issues that run through much of the literature.

Samples

The sampling of the respondents and participants in many of the studies is cause for concern in the research. Often it seemed that the parent most easily recruited, usually the mother, is the one accompanying the child and siblings to the clinic. Although valuable, data provided by the same parental figure in each family system may be biased (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Horwitz & Kazak, 1990; Sargent et al., 1995). Many of the studies were conducted on primarily heterogeneous populations that are subsumed under a single pediatric diagnosis of childhood cancer. Researchers may incorrectly attribute variance in psychological outcomes to a pediatric condition when local variation in the characteristics of conditions, recruitment, and/or family environmental characteristics exert more powerful influences (Drotar, 1994).

The sample demographic data is fairly uniform throughout most of the literature. The participating families are generally middle-class, church-oriented, English-speaking, Caucasian in ethnicity, with married parents who are young to early middle age, and with a broad range of educational experiences (Kazak et al., 1997; Sargent et al., 1995; Speechley & Noh, 1992; Zeltzer et al., 1996). Many of the studies lack generalizability due to sampling from single sites and limited populations (Brett & Davis, 1988; Horwitz & Kazak, 1990; Martinson, Gilliss, Colaizzo, Freeman, & Bossert, 1990; Walker, 1988). Other studies have good generalizability, due to sampling over a broad population, using multiple sites, and incorporating many variables (Cohen et al., 1994; Sahler et al., 1994; Sargent et al., 1995; Zeltzer et al., 1996).

In conclusion, the respondents most often used in the studies were mothers, which may be due to the fact that they were more readily available to be used in research studies. Additionally, the pediatric diagnoses were fairly heterogeneous whereas the demographic data was similar throughout most of the families, which may leave the results of these studies tenuous and with limited generalizability.

Procedures

A limitation that most studies face is that of sampling bias due to self-selection. With the relatively small number of childhood cancer diagnoses, it is difficult to obtain adequate sample size. Perhaps the confusing and conflicting results of studies that have focused on outcome variables stem from the effects of confounding variables. These confounding variables may include sampling of siblings, as well as decisions regarding which parent provides data. For example, the parent reporting on the siblings may be the one accompanying the ill child to the clinic, but may not be the parent who knows the healthy siblings' emotional, behavioral, and psychological functioning the best. The studies did not assess or perhaps were unable to assess the characteristics of those who did not respond or dropped out of the studies.

The research design used most often was cross-sectional. However, it is not a substitute for much needed longitudinal research, which would greatly assist in studying the trajectory of the siblings' ability to cope, adapt, and adjust over a long period of time. Although longitudinal studies would assist the research greatly in this area, there are many confounding problems and difficulties in conducting such research. In addition, the studies often combined children of diverse developmental stages without careful consideration of developmental issues. For example, there are vast developmental

differences when researchers include both siblings who are young (e.g., 7 to 12 years old) as well as adolescents (e.g., 13 to 18 years old) in the same research design and place them in the same reference group.

Another limitation to be taken into account, when reviewing the literature, is the inability to control the time elapsed between when the child diagnosed with cancer has successfully completed treatment and when the siblings and parents participated in the research project. For example, it is unknown whether the siblings and parents would respond differently if the child were a 1-year or 5-year cancer survivor. The difference in time elapsed may confound the results of the siblings' and parents' responses to their ability to cope, adapt, and adjust to the child surviving cancer.

There are several plausible reasons why the research concerning either the vulnerability or resilience of siblings and parents of chronically ill children may be inconsistent, due in part to the bias of the researchers (Kazak & Nachman, 1991; Leonard, 1991). Earlier literature predicted that the presence of a chronically ill child would have a negative impact on families and result in psychopathological reactions. This deficit model toward families has now been challenged repeatedly in research showing similarities between families with and without ill children (Cohen et al., 1994; Horwitz & Kazak, 1990; Kazak & Meadows, 1989; Sargent et al., 1995).

In conclusion, the small number of children diagnosed with cancer each year limits researchers, since access to a considerable sample size is hampered. To conduct research on siblings' functioning, a cross-sectional design seems to be the vehicle of choice by most researchers. Although longitudinal studies would be ideal, there are many obstacles in conducting this type of research. In recent years, the research

paradigm in studying healthy siblings who have another sibling surviving cancer has shifted toward looking at vulnerability and resilience among the healthy siblings. In years past, the research paradigm saw cancer as having only a negative impact on the healthy siblings, one which led to psychopathological problems.

Assessment

In considering assessment issues that run throughout the literature, although many studies incorporated standardized self-report measures, there was considerable use of nonstandardized self-report measures and semi-structured interviews to assess coping, adapting, and adjusting. There were also newly designed questionnaires developed by researchers, based on previous studies and their own experience working with these types of populations. The use of the new instruments limits the objectivity of the data gathered. Additionally, the downfall of these approaches is the lack of well-structured comparison groups that would be able to shed light on how unique or typical are the reported experiences of siblings and parents of children with cancer. However, the information obtained from newly developed self-reports, semi-structured interviews, and questionnaires is invaluable. These measures capture the experiential component of the respondents and may lead to the development of specific instruments to use with childhood cancer patients' families. For the most part, information from others outside the family is sparse. Only two studies were found (Sahler et al., 1994; Zeltzer et al., 1996) that assessed others outside the family such as teachers, physicians, nurses, or other mental health professionals' perceptions on the coping, adapting, and adjusting of siblings of a survivor of childhood cancer.

There were many different standardized self-report measures used throughout the literature reviewed, with only three measures used more than once. The three measures used by several different researchers were the Child Behavior Checklist (CBCL), the Family Adaptability and Cohesion Scale –Version II (FACESII), and the Coping Health Inventory for Parents (CHIP). The CBCL, developed by Achenbach and Edelbrock (1983, 1987; as cited in Cohen et al., 1994), is a 113-item instrument that yields subscales for externalizing problems (e.g., aggression) and internalizing problems (e.g., depression) representing dimensions of a child's behavior. Achenbach and Edelbrock provided extensive reliability and validity data on the three forms of the CBCL: the Parent Report Form, the Teacher Report Form, and the Youth Self Report. In one study, Zeltzer et al. (1996), utilizing the Parent Report Form and the Youth Self Report, used these forms to cross reference the data in order to determine the correlation between the parents and the siblings report.

The FACES II, developed by Olsen, Portner, and Bell (1982; as cited in Kazak & Meadows, 1989), is based on Olsen's Circumplex Model of Marital and Family Systems. The model is based upon the importance of cohesiveness and adaptability in family functioning. This instrument has been used in other studies of cancer patients and their families. The authors posit four levels of cohesion (disengaged, separated, connected, enmeshed) and four levels of adaptability (rigid, structured, flexible, chaotic), with midrange values expected to be most adaptive. Barnes and Olsen (1985; as cited in Kazak & Meadows, 1989) demonstrated good validity and reliability of this scale.

The CHIP, developed by McCubbin and Patterson (1981; as cited in Birenbaum, 1990), is a questionnaire to assess family coping with three specific scales:

(a) maintaining family integration, cooperation, and an optimistic definition of the situation, (b) maintaining social support, self-esteem, and psychological stability, and (c) understanding the medical situation through communication with other parents and consultation with medical staff. Internal consistency reliabilities using Cronbach's alpha for the three scales are .79, .79, and .71, respectively, as reported by McCubbin and Patterson.

By using standardized measures, the researchers were able to obtain reference groups with which to compare the results of the siblings' and parents' responses. One advantage of using diverse standardized measures is that the researchers can obtain information concerning coping, adapting, and adjusting from many different viewpoints. A disadvantage to this practice is that a majority of these studies are not duplicated, using the same instruments, possibly due to the researchers' bias toward using other instruments. In addition, it is unknown whether the various instruments are testing the same construct of coping, adapting, and adjusting as the other tests.

The operationalization of variables is not uniform throughout the literature. There is conflict over the criteria used to define coping, adapting, and adjusting. Some of the inconsistency of findings of adapting and coping may be partly accounted for by differences in definitions of and instruments used to measure adaptation and coping (Kazak & Nachman, 1991; Sargent et al., 1995). There is a lack of uniformity in assessing variables that mediate the stressful conditions imposed by the presence of childhood cancer in the family. The dominant model of conceptualizing adaptation is the function of adjustment prior to a stressful event and subsequent resourcefulness in adapting after the event (Sargent et al., 1995). Two important moderating variables that

have been discussed in the literature are social supports and coping styles. Social support refers to the perceived availability of friends and family members to help a person cope with stress. This social support may buffer the negative impact of stressful life events, thus protecting the person from the effects of stress. Coping styles are the cognitive and behavioral response patterns used to manage one's problems (Lazarus & Folkman, 1984).

Therefore, the use of more standardized tests would allow researchers to compare the experiences of the healthy siblings to a normed sample, which would aid researchers in understanding the impact of being in a family with a sibling surviving cancer. However, the use of nonstandarized instruments and semi-structured interviews may be equally beneficial in that these measures may capture the experiential component of the healthy siblings' experience and may lead to the development of more illness-specific instruments. The lack of repeated use of standardized instruments by the various researchers may be due in part to the differences they have in defining the variables they want to observe and test. Additionally, gathering data from family members with self-report measures only may skew the data. It would be beneficial, as well as more robust, if information were also obtained by others (e.g., physicians, nurses, teachers, and friends of the family).

Siblings

With the overall 5-year survival rate of children with cancer over 60%, the long-term impact of this on-going stressor on the healthy siblings' ability to cope, adapt, and adjust to a sibling surviving childhood cancer is of increasing concern. Although the psychosocial difficulties children with cancer and their families experience continue to be

acknowledged, the shift in research today is to focus more on vulnerability and resiliency rather than psychopathology. Research findings have consistently indicated that the family crisis of childhood cancer can have a profound impact on siblings' psychosocial functioning (Daniels, Moos, Billings, & Miller, 1987; Sahler et al., 1992). In summarizing past studies, research on siblings of children with cancer from 1950 to 1985 had consistently identified psychosocial problem areas. These included (a) feelings of resentment, (b) negative self-image, (c) anger, (d) anxiety, (e) depression, (f) fear of the sibling's death, (g) fear of their own death, (h) jealousy, (i) guilt, (j) poor peer relationships, (k) psychological and physical isolation from the parents, and (l) a wide range of behaviors aimed at obtaining parental attention (Gallo, 1988; Walker, 1990). However, the prevailing research paradigm during this time was that the presence of a chronically ill child would have negative psychosocial consequences on siblings. In addition; when this research was conducted, a majority of the health care provided to these children with cancer was palliative, and emotional support was provided to the siblings coping with their ill sibling's terminal disease and inevitable death. Since 1985, the focus of research has changed. Although it is still important to understand the psychosocial problems associated with a family member with childhood cancer, the research paradigm is shifting to see what the positive effects of having a family member with cancer are for siblings. Gallo and Walker both reported that some of the research showed that positive effects of the cancer experience for the healthy siblings included (a) an increased ability for empathy, (b) sensitivity and an increased ability to cope with stressful and fearful situations, (c) improved sibling relations, (d) enhanced personal

maturation and self-concept, (e) increase in family cohesion, and (f) a perceived ability to cope with negative changes that do occur.

In their research, Lobato, Faust, and Spirito (1988) developed a variable matrix in order to investigate the effects of chronic disease on sibling relationships. The first matrix is a large set of family background variables upon which the chronic disease is imposed. There are three main subgroups: (a) sociodemographic, (b) individual and family adaptive and functional patterns, and (c) functional patterns imposed by the chronic disease. The sociodemographic characteristics included (a) socioeconomic status, (b) birth order, (c) age spacing, (d) gender, (e) age of patient and siblings, (f) family size, and (g) marital status. The factors associated with the individual, family adaptive, and functional patterns included (a) sociocultural influences, (b) family social network, (c) family coping style, (d) physical health of family members, and (e) psychological resources of family members. The last subgroup, functional patterns imposed by chronic disease, included (a) disruption in family routine, (b) contact with other families with affected children, (c) patient adjustment to and acceptance of the disease, (d) parent attitudes and expectations of patient and siblings, and (e) parent, sibling, and patient understanding of the disease. All in all, these researchers felt that each of these unique variables has a particular impact on all the family members and needs to be considered to one degree or another. Although background factors can undoubtedly influence siblings' response to the ill child, reactions are hardly uniform. A primary reason for variation in siblings' effects may be more dynamic aspects of individual and family adaptation and functioning. Some forms of adaptational functioning and interaction are common to families and others occur specifically in

reaction to the presence of a cancer. The quality and strength of the parental relationship has permanent effects on every child's development and should be a focus of attention within the sibling context as well.

The second matrix was comprised of characteristics of the disease itself that are superimposed upon the family and its ability to function. The characteristics of the certain diseases vary greatly and need to be taken into consideration, including the onset, etiology, course or phase, prognosis, and functional complications. Time of onset likely exerts a strong and direct effect on the sibling relationships. The quality of the children's relationship prior to the illness would be likely to affect their adaptation. Etiology may also mediate impact in important ways, such as the possibility of parental shame and guilt, stemming from the belief that they have somehow caused their child's disease, which may have both subtle and obvious effects on parenting style.

Adjustment

Although many siblings of childhood cancer survivors appear to benefit emotionally and psychologically from this cancer experience, the research has also uncovered adverse psychological outcomes, including increases in aggressive behavior, poor peer relations, anxiety, somatization, and depression (Lobato et al., 1988). Despite some adverse outcomes, these researchers noted that reactions appeared to be more related not to sibling constellation variables, but rather to general family factors such as socioeconomic status, mother's social support, and parent reaction to the disease. However the absence of one-to-one correspondence between presence of emotional disturbance in siblings and the presence of childhood cancer in the family underscores the notion that there are no clear, simple, linear relationships between the level of adaptation

and any of the various sibling characteristics. Thus, the impact of childhood disease on siblings may best be conceptualized as a risk or stress factor, the significance of which is mediated by other individual and family characteristics and resources.

Prior to 1990, studies of siblings of children with cancer reported that approximately 50% of them experience adjustment problems (Carpenter & Levant, 1994). However, most studies did not take into account the rate of adjustment problems among the healthy siblings prior to their sibling being diagnosed with cancer. An exception to this problem, the study by Sahler and Carpenter (1988) of 82 siblings of children with cancer, found that 22 % of the siblings were reported by their parents as having had adjustment problems prior to the cancer diagnosis. Thirty-nine percent of the siblings had no prior adjustment problems, but were reported by parents to have had adjustment problems following diagnosis, and the remaining 39 % were reported to have had no adjustment problems either prior to or following the diagnosis of cancer. There is no uniform or direct relationship between a child's illness and psychopathology among one's siblings. In general, group research does not support the popular belief that siblings of chronically ill children exhibit more problems in overall psychological adjustment than do siblings of able children (Kotchick, Forehand, Armistead, Klien, & Wierson, 1996; Lobato et al., 1988; Sahler et al., 1994).

Emotional and behavioral adjustment. In a comprehensive study representing a diverse cross-section of the population of the United States, from seven different pediatric oncology treatment centers, Sahler et al. (1994) studied 254 siblings (mean age = 10.65 yrs., range in age from 5 to 17 years old) from 179 families with a child diagnosed with cancer. The researchers assessed the frequency and intensity of

emotional/behavioral distress in siblings of children with cancer. The mother was the parental respondent in 170 of the 179 families. Matched controls were obtained from respondents to the Child Health Supplement of the National Health Interview Survey administered in 1988. The researchers organized and defined the interrelationships among the variables and constructs to be investigated, which included demographic data and use of the model originally adapted from the work done by McCubbin (1991) and his colleagues in the area of family systems theory (cited in Sahler et al., 1994). This theory emphasized the complex, reciprocal interactions that occur between individuals, among family members, and between family units and the larger social environment.

The specific measures used by Sahler et al. (1994) included the National Health Surveys and standardized and nonstandarized instruments. To determine differences between siblings and children in the general population, the researchers administered specific sections of a variety of national health interview surveys to provide sibling data that could be compared to that from matched control samples. A number of standardized instruments were administered including the CBCL, Teacher Report Form, and the Youth Self Report (Achenbach & Edelbrock 1983, 1987; as cited in Sahler et al., 1994), the CHIP (McCubbin and Patterson 1981; as cited in Sahler et al., 1994), the Family Expressiveness/Conflict Scales (questions on these scales were derived from a series of factor analytic studies of four well-known self-report measures and assess 15 dimensions of family functioning with family expressiveness and conflict constituting 2 of the 15 dimensions; acceptable psychometric properties was reported by researchers), and the Health Resources Inventory (it measures a variety of children's school-related competencies and is reported to have good reliability and validity measures reported by

the researchers). The nonstandardized instruments that were study-specific included structured interviews, and the Feelings and Attitudes about My Brother's/Sister's Cancer questionnaire by Carpenter & Sahler (1991; as cited in Sahler et al., 1994). This questionnaire was used to assess siblings' feelings, attitudes, and reactions to cancer in the family and has internal consistency alpha reliability coefficient for interpersonal, intrapersonal, communication, and fear of disease factors of .86, .80, .67, and .65, respectively, as reported by Sahler et al. (1994). The nonstandardized instruments also included other self-report questionnaires measuring family relations, personal autonomy, and parental control. Non-family-derived data was obtained from questionnaires completed by the siblings' teachers or guidance counselors regarding school functioning and the primary care physician regarding physical and mental health.

The overall prevalence of emotional/behavioral problems in siblings of children with cancer pre- and postdiagnosis was 16.9% (43) of the population sampled. However, when the problems were divided into problems that preexisted the diagnosis of cancer and those with onset of problems since diagnosis, 7.7% of the siblings had preexisting problems. This baseline prevalence of children with behavior problems was not significantly different from that in the general population, 6.3%, χ^2 (3, $\underline{N}$ = 254) = 0.46, $\underline{ns}$. However, 9.2% of siblings developed problems after diagnosis (on average, 22.5 months at the time of the study), thus more than doubling the number of siblings with problems as perceived by parents. When age and gender differences on the incidence of new-onset problems is taken into consideration, the increase in problems is not uniform. The most dramatic increase was in younger girls ($\underline{n}$ = 77, age 4 to 11 years), with preexisting problems at 2.6%, increasing to 9.4% of the total population postdiagnosis.

Despite this marked increase, the overall prevalence of problems remained lowest in this group of siblings. In contrast, younger boys (n = 76, age 4 to 11 years) had both the highest baseline prevalence (11%) and the highest overall prevalence of behavior problems (25%).

Besides reporting the simple prevalence rates of emotional/behavioral problems, the researchers wanted to consider the frequency and intensity of undesirable behaviors to provide higher order information about the level of adaptation. The Behavior Problems Scale that was developed for use as part of the National Health Interview Survey was comprised of items derived from and identical with a subset of the Child Behavior Checklist. The 28 items on the scale are summed to derive a Behavior Problems Index (BPI). Sahler et al. (1994) reported that tests of internal consistency reliability of the BPI revealed α coefficients of .89 and .91 for young children and adolescents, respectively. Parents of children in the sibling sample, as a whole, endorsed a significantly higher level (intensity) of behavioral distress than did parents of children in the national survey comparison sample. The paired t test was used for comparison to avoid the issue of multiple comparisons. Therefore, one-way pairwise analyses were not performed. Hence, a more conservative approach of comparing targeted subgroups (e.g., same age, different gender) with individual t tests was chosen. Differences were most marked for younger boys, $t = 5.28$, $p < .001$, although a marginally significant difference, $t = 2.19$, $p < .05$, between older girls and their matched controls was noted. When siblings were divided by age relative to the ill child, brothers, aged 4 to 11 years, whether younger or older than the child with cancer, were especially prone to develop problems compared to

their matched controls. A similar analysis of sisters, ages 4 to 11 years, revealed no significant differences.

There could be a number of developmentally associated explanations that may account for the difference between brothers and sisters ranging in age from 4 to 11 years. For example, two common illustrations included psychosocial and expressive immaturity of the boys relative to girls of the same age and the aggression that is common among preadolescent boys. The second gender/age finding is that older girls appear to experience increased distress. This may reflect the fact that such girls may be expected to assume increased caregiving and housekeeping responsibilities to assist parents who are preoccupied with care of the ill child, typically at the cost of participating in social activities with peers.

In conclusion, the findings of the Sahler et al. (1994) study indicated that, according to parent report, siblings of children with cancer, as a whole, experience heightened emotional/behavioral distress during the period of 6 to 42 months after diagnosis when compared to children in general. However, it appears that some subgroups may be at particular risk, especially brothers ranging in age from 4 to 11 years. When all the sibling variables are analyzed, the two most important predictor variables for the presence or absence of problems arising after diagnosis appear to be the compound variable, gender/age and the presence of problems existing before diagnosis. With regard to siblings with previously existing problems (n = 99), 40% (39) of siblings with such problems are likely to develop emotional/behavioral distress of sufficient magnitude to warrant intervention, whereas only 2% (3) of siblings without preexisting problems (n =139) are likely to do so. This within-group difference among the cancer

families in the rate of reported problems supports the validity of the finding. That is, the idea that the parents would see the well sibling as psychologically vulnerable, just because there is cancer in the family, is not supported.

Cohen et al. (1994) investigated the relationship between sibling adjustment to pediatric cancer and a large number of family and child variables in a sample of 129 siblings of pediatric cancer patients. The results indicated that a significant number of siblings did, indeed, display adjustment problems compared to the norms of the widely used Child Behavior Checklist. The following family and coping variables were found to be significant predicators of positive sibling adjustment: (a) absence of parental depression, (b) good marital adjustment, (c) higher family income, (d) higher levels of neighborhood/community social support, (e) effective parent-sibling communication about the illness, and (f) longer time since diagnosis. The results of Cohen et al. (1994) are similar to that of a study conducted by Evans, Stevens, Cushway, and Houghton (1992) in that, although many siblings experience adjustment problems, many also cope adequately, and the relationship between the stress of having pediatric cancer in the family and sibling adjustment is neither simple nor direct.

In summary, it is difficult to determine the specific impact that children's diagnosis of cancer has on their siblings' emotional and behavioral adjustment. Research findings before 1990 indicated that over 50% of siblings experienced adjustment problems. However, there was no attempt to control for the independent variable of preexisting adjustment problems prior to another sibling's being diagnosed with cancer. The range of siblings having had adjustment problems prior to their sibling's being diagnosed with cancer was 20% to 40% of the sample population. Although parents of

siblings endorsed a higher level of behavioral distress than did the parents in a comparison sample or a normed sample, the baseline rate of behavior problems was not significantly different than that of the general population (Cohen et al., 1994; Sahler et al., 1994). Moreover, the range of siblings having no adjustment problems prior to or following the diagnosis of cancer was from 40% to 50% of the sample population.

Preschool siblings' adjustment. For the most part, there has been little attention in the literature given to preschool siblings' adjustment. More often there are broad age ranges used in studies, which obscure developmental differences in adjustment (Horwitz & Kazak, 1990). In their study, Horwitz and Kazak wanted to describe the predominant patterns in families of children with cancer, integrating a family systems view with sibling adjustment and a normative-developmental perspective. To investigate family adjustment to stressful life events, Horwitz and Kazak used the Circumplex Model of Marital and Family Systems (Olson, 1986; as cited in Horwitz & Kazak, 1990), which included two dimensions: (a) adaptability (the family system's flexibility and ability to change) and (b) cohesion (the degree of emotional separateness or connection in a family). Twenty-five families participated in the study and twenty-five 3 to 5-year-old siblings of children receiving routine health care composed the control group. The instruments used in the study included: the Child Behavior Checklist; The Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (this scale is designed to measure young children's self-perceptions with four subscales including cognitive and physical competence and peer and maternal acceptance); and The Parents' Report of Prosocial Behavior (a questionnaire designed for this study to evaluate the frequency of prosocial behaviors that have often been observed in preschool children).

The study also used The Global Alike-Different Scale and Sibling Attributes Scale, which was adapted from Schacter, Shore, Feldman-Rotman, Marquis, & Campell (1976; as cited in Horwitz & Kazak, 1990). This scale was a parent-report questionnaire used to assess perceived likeness or difference in siblings. Additionally, the Different-Same Game (an interview constructed for this research, which has a 10-item, illustrated format for preschoolers, showing pairs of "siblings") and the Family Adaptability and Cohesion Scale-Version II were also utilized.

Preschool siblings of children with cancer showed no major behavioral or social problems in comparison with siblings of healthy children or published norms. Siblings in the oncology group were rated as having fewer total behavior problems than comparison siblings, $F(1,47) = 3.78$, $p < .05$. They also possessed psychosocial assets including positive self-perceptions and social competence. Furthermore, the siblings had significantly higher scores on five of the prosocial behaviors including helping, $F(1,25) = 7.73$, $p < .01$, giving gifts, $F(1,25) = 6.03$, $p < .01$, praising, $F(1,25) = 7.33$, $p < .01$, sharing, $F(1,25) = 3.32$, $p < .05$, and showing affection, $F(1,25) = 3.63$, $p < .05$, as compared to the control group. These higher rates may be a function of increased opportunities for prosocial behavior. With an ill child, demands increase, and family members may give each other emotional and tangible support during difficult times. As foreseen, more families of children with cancer obtained either very high or very low adaptability scores. In the sibling group, 56% were classified as either "rigid" or "chaotic," whereas in the comparison group only 20% were in either extreme category, $\chi^2 (3, N=50) = 10.70$, $p < .05$. Although the distribution of adaptability scores in this sample differs from the norms that Olsen produced and from that of the comparison

group, the siblings were generally psychologically well adjusted (Horwitz & Kazak, 1990).

Other family dimension results included using Pearson product-moment correlations which showed significant associations between Adaptability and Total Behavior Problems, $r = -.41$, $p < .05$, and Internalizing, $r = -.49$, $p < .05$. Similarly, Cohesion was significantly correlated with Total Behavior Problems, $r = -.65$, $p < .01$, Internalizing, $r = -.63$, $p < .01$, and Externalizing, $r = -.56$, $p < .01$. Higher scores on Cohesion and Adaptability were thus associated with fewer reported behavior problems, but this linear relationship did not hold for other adjustment variables. Horwitz and Kazak (1990) indicated that, because of the moderate cell sizes, meaningful interpretation of ANOVA could not be performed.

The data from the study by Horwitz and Kazak (1990) showed that the preschool siblings of children with cancer were generally psychologically well adjusted. These siblings had fewer behavior problems, possessed more prosocial behaviors, had more positive self-perceptions, and had social competence. The families in this study did not fall within the "normal" families that Olsen used to norm his test that shows that higher adaptability and cohesion are related to better functioning. Horwitz and Kazak indicated that their findings should be interpreted in terms other than normal versus abnormal, but did not indicate what terms to use. First, an extreme adaptability level may mean families are adjusting quite adequately to the stress of having a child with cancer. Second, in the closer, more involved ("cohesive") family, siblings' needs and concerns may be more likely to be addressed and parents may be more aware of potential problems. "Normalcy" in these families may differ greatly both across and within illness groups.

These patterns should be the focus of study as varied styles may fluctuate and be specific to childhood cancer.

In conclusion, preschool age siblings did not show evidence of major behavioral or social problems compared to siblings from healthy families. In fact, these siblings had fewer behavior problems and also evidenced more prosocial behaviors and positive self-worth. The evidence of fewer problems and more prosocial behaviors may be indicative of how the siblings have coped, adapted, and adjusted to the cancer experience. Horwitz and Kazak (1990) found that the more families were cohesive and adaptable the less likely they were to have behavior problems with healthy preschool siblings.

It appears that younger children, especially boys (age 4 to 11 years) are at more risk for adjustment problems either emotionally and/or behaviorally, according to the study by Sahler et al. (1994). Horwitz and Kazak (1990) found that preschool age siblings of children with cancer had fewer total behavior problems and demonstrated more prosocial behaviors toward others. Unlike the Sahler et al. (1994) study, Horwitz and Kazak (1990) did not investigate the gender differences in their sample. However, the current research findings suggested that siblings of a childhood cancer survivor do not exhibit problems in their overall psychological adjustment compared to siblings in the general population.

Coping

The same database that was used in the Sahler et al. (1994) research study was also used in the Sargent et al. (1995) study to elicit thoughts and feelings about effects of cancer from siblings. The researchers used a questionnaire comprised of nine questions to obtain information about the difficulties and benefits perceived by the healthy siblings

with regard to having a sibling diagnosed with cancer. The questionnaire also addressed specific areas of coping. The final question asked what advice the sibling would give to another sibling of a child with cancer. Two reliability checks were conducted on the verbatim responses of the siblings' answers that were grouped into psychologically meaningful categories. There was a 75% to 98 % agreement, with a median of 82%, between Janice Sargent and a research assistant as to the meaningfulness of the responses.

The frequencies of coded responses for each question were analyzed using the chi-square statistic. The researchers looked at the difference between ages of the siblings (younger than 12 years vs. 12 years and older) as well as the difference between age group and gender. Older siblings reported that the "biggest change for them" (Question 1) since the diagnosis of cancer was becoming more compassionate, caring, and mature, whereas the younger group reported an increase in negative feelings or no change, χ^2 ($\underline{N}$ = 8) = 47.10, $\underline{p} < .001$. Similarly, when considering the "biggest change for family" (Question 2), older siblings stated that their families had become closer, whereas younger siblings frequently reported no change or could not respond at all, χ^2 ($\underline{N}$ = 8) = 40.31, $\underline{p} < .001$. When asked if "something good" (Question 4) had come from the cancer experience, older siblings again more frequently noted their families had become closer and that they had experiences they otherwise would not have had, whereas younger siblings frequently did not respond, χ^2 ($\underline{N}$ = 4) = 43.31, $\underline{p} < .001$. Older and younger groups also differed in regard to what they felt they had "handled worst," (Question 8), χ^2 ($\underline{N}$ = 5) = 19.80, $\underline{p} < .001$. Finally, age groups differed in their "advice to another sibling," (Question 9) of a child with cancer, χ^2 ($\underline{N}$ = 6) = 26.17, $\underline{p} < .001$. Older

siblings suggested ways of coping with the stress such as being patient and not getting hopes up too high, whereas younger siblings would be directly empathic with the other sibling, for example, sending the sibling a card or telling the sibling, "I know how you feel." Other younger siblings had difficulty responding at all to this question.

There were significant differences in the age (< 12 years old vs. > 12 years old) by gender interaction. Twenty-nine percent ($n = 22$) of the younger girls reported that family separations represented the biggest "change for their families" compared to less than 17% for the other three age by gender groups, $\chi^2 (N = 21) = 59.12$, $p < .001$. When asked if "something good" had come from the cancer experience, older girls most often said that something good had happened, $\chi^2 (N = 12) = 47.62$, $p < .001$. Whereas older boys reported most frequently that they handled "treatment effects least well," younger girls least often reported so, and older girls most often reported they had more difficulty with their own negative feelings, $\chi^2 (N = 15) = 26.90$, $p < .05$. For example, these female siblings worried about feeling angry, impatient, and guilty. The difference in these responses suggested that gender differences in reactions to illness in the family may begin as early as adolescence. Young boys least often were able to "give advice" to another sibling of a child with cancer for ways to deal with the stress of cancer in the family, $\chi^2 (N = 18) = 31.10$, $p < .05$.

The siblings in the Sargent et al. (1995) study reported (a) distress about family separations and disruptions, (b) lack of attention to them and focus of the family on caring for the ill child, (c) negative feelings in themselves and other family members, (d) changes in the ill child's behavior, and (e) cancer treatments and adverse side effects. Of particular interest was the absence of response about the lack of information about

cancer reported by the siblings. On the positive side, siblings reported that (a) they had become more compassionate and caring, (b) family members were closer to each other, (c) they had experiences they otherwise would not have had, and (d) they felt they had been helpful to their ill sibling and to their families.

Differences in responses were most often related to age of the siblings or to an age by gender interaction. Older siblings (> 12 years old) were far more likely to be described as positive perceivers than younger siblings. The level of maturity of the sibling and the ability to transcend day-to-day stressors facilitated a more positive outlook. In addition, older siblings are more likely to have had more independence and support from activities outside the home that could buffer the effects of having a sibling with cancer. The preponderance of older siblings in this study suggested that being more mature had advantages in coping with the stress of cancer in the family.

Sahler et al. (1994) found the siblings in this sample to have a higher frequency of behavior problems than the control group from the general population. The group at highest risk for problems was boys age 4 to 11 years old. The young boys' paucity of positive answers to the interview items in the Sargent et al. (1995) study and their inability to offer advice to other siblings is consonant with parental reports of their heightened distress (Sahler et al., 1994). Both young boys and girls were unlikely to be described as positive perceivers (Sargent et al., 1995). Developmentally, young children are more sensitive to disruptions in their lives and have more limited strategies and resources for coping with stress than older children. In this sample, Sargent et al. noted that younger siblings had the greatest difficulty expressing their thoughts and feelings, most repeatedly unable to give a response. They stated that it is important when

interviewing younger children to inquire directly about their stress, rather than asking open-ended questions exclusively to which they may be unable to respond.

The purpose of the longitudinal and nonexperimental study conducted by Martinson et al. (1990) was to identify the reactions of family members to the experience of having a child with cancer in the family. The sample included 40 midwestern families with a child between birth and 16 years newly diagnosed with cancer. The ill child and parents in each family were interviewed at the time of diagnosis and annually for the next 5 years. Prior to the time of the 3rd-year interview, the researchers included the siblings in the interview process. At the time of diagnosis, the siblings ranged between 3 and 9 years of age. At the completion of the 5-year study, there were nine siblings with a living child and seven siblings with a deceased child. The data presented here will focus only on those siblings with a living child. The open-ended, semi-structured questions were based on the literature and prior work of Dr. Martinson to elicit responses regarding the siblings' understanding of the diagnosis, hospitalization, treatment, prognosis, and the effect these events have on themselves and on their families' lives. Each interview was transcribed from tapes and analyzed separately by two members of the study team using the method of content analysis. Only the themes identified by both members were retained in the analysis.

Since the number of siblings with a live child was very small (N= 9) and the sample was taken from one geographical location, the generalizability of their explanations of their responses and emerging themes are tentative. The research findings seemed to suggest that the age of the sibling included in the study had a great deal of influence on the type of responses given, especially in an interview format, as well as

their understanding of the cancer experience. This may be due to the siblings' cognitive functioning and ability to engage in abstract thinking, as well as their developmental level. One interesting theme discovered among the siblings was that only 4 (44%) were able to verbalize personal difficulties. Those who answered, referred in one way or another to (a) the lack of power they felt in the situation, (b) not being present in the hospital, (c) not being included in conferences with the doctor, and (d) not knowing what to say to friends. A parallel issue was feelings of jealousy which, however, often could not be acknowledged until the ill sibling had recovered. Some other emerging themes noted were the need for more information about cancer and feeling displaced and unimportant in the family. Martinson et al. (1990) stated that "in a family that has faced life-threatening illness, and in which the possibility of relapse remains, children can be expected to withhold expression of their own concerns as being somehow less important compared to the child with cancer" (p.188).

Brett and Davis (1988) investigated healthy siblings' changing appraisals of the significance of childhood leukemia 5 years or more following diagnosis of their other sibling. The siblings, in this study, were older than 9 years of age. The researchers used structured interviews to look at the thoughts and worries of these siblings. With a small sample size of 10, the generalizability of the results are limited. The data revealed that parental control of information about the ill child is common and served as an anxiety-reducing strategy for parents, but because siblings lack the external avenues for information and support available to their parents, family communication may contribute to siblings' disease-related ignorance and isolation within the family. Hence, siblings may create their own explanations.

Walker's (1988) qualitative study of 26 siblings of children with cancer (mean age = 11.2 years, SD = 3.8 years) led to a taxonomy of children's coping strategies. The taxonomy was divided into two main domains: cognitive and behavioral, with each domain having three subheadings. The cognitive domain included intrapyschic, interpersonal, and intellectual coping efforts and the behavioral domain included self-focusing, distraction, and exclusion coping efforts. The results of this study found that the major coping strategies siblings used that were most effective were (a) expressing emotions, (b) empathizing toward other siblings, (c) denying and regressing, (d) talking to or being with others for support, (e) seeking out information about cancer, (f) fantasizing, and (g) engaging in solitary and group activities used for distraction.

Sahler and Carpenter (1989) evaluated a unique 5-day residential camping program for siblings of children with cancer. Their naturalistic study was undertaken to evaluate the effect of the program (a) on the level of medical knowledge, (b) on the perceptions of how the cancer experience affected the individual, and (c) on the participant's mood state. The intent of their investigation was to systematically assess the influence of the camping experience as it was designed. Thus, there was no attempt to control for confounding variables or to assign siblings to intervention groups. There were 90 campers who ranged in age from 6 to 17 years. The authors developed the assessment questionnaire, with consultation from oncology specialists and several siblings. Each item of the questionnaire was rated using a Likert-type scale, ranging from 1 (never) to 5 (always). The questionnaire assessed two primary content domains: (a) medical knowledge and perceptions and (b) affective responses. The authors reported an interrater reliability of 85% for the questions pertaining to medical knowledge. Factor

analysis revealed four primary factors for perceptions of disease influences, which were interpersonal, intrapersonal, communication, and fear of disease. Global responses to the influence of cancer were assessed using eight positive and six negative mood states. The particular mood states were chosen because of their face validity and sensitivity in detecting distress. A parent questionnaire was used to assess perception of specific and global responses of the siblings to the cancer experience.

Analyses of questionnaire data from 90 campers before and after their camp experience, using paired t tests (one tailed), revealed that desirable changes occurred in each of these areas (medical knowledge, perceptions, and affective responses) and were sustained for at least the 3-month follow-up period. No significant negative effects were found regardless of camper age, adaptational status, or previous camp experience. With respect to medical knowledge, the camp seemed to be most beneficial to younger campers (< 12 years) who had more limited understanding and who may have responded more favorably to the hands-on, concrete demonstrations used. When time since diagnosis was controlled for, to ascertain potential effects of ongoing instruction about or familiarity with the disease, no correlation was found beyond that related to age. This seems to be consistent with other research findings that older siblings (> 12 years) seem to understand the disease more fully than younger siblings regardless of the time since diagnosis. Regardless of how the camper population is divided for analysis, the major consistent influence of the camp was on intrapersonal attitudes toward cancer (feelings of sadness and anger, preoccupation with the disease). This was not unexpected given the structure of the camp, which focused on self-help strategies.

In summary, the research of Sargent et al. (1995) indicated that older siblings (greater than 12 years of age) were able to cope more effectively with sibling cancer than younger siblings. Developmentally, older siblings may be better at rising above the stress of the cancer, are able to verbalize their feelings both positive and negative about the cancer experience, have more strategies and resources for coping and support from outside activities, all of which can act as a defense against the effects of the cancer experience. Although young siblings had more difficulty coping, they were able to be empathic to the ill sibling. Both positive and negative effects were noted in the healthy siblings, yet Martinson et al. (1990) stated that the siblings' willingness to disclose more negative emotions may be withheld if there is any indication of relapse possible. Therefore, the siblings may be left to cope more on their own or seek assistance from outside the family. Additionally, the research indicated that coping strategies used included both cognitive and behavioral techniques. Furthermore, when age appropriate information about their sibling's illness was disseminated to the healthy siblings, they were better able to cope with the illness and not rely on their own, often false, explanations.

Physical Health

Although there have been numerous studies on the psychological impact of chronic childhood illness on healthy siblings, the impact of the illness on the physical health and well-being of healthy siblings has received little attention (Zeltzer et al., 1996). Additionally, the financial and emotional burdens placed on parents of chronically ill children may leave limited reserve for the healthy children in the

family, especially if they appear relatively healthy and do not complain about physical symptoms.

In a comprehensive study representing a diverse cross-section of the population of the United States, from seven different pediatric oncology treatn ent centers, Zeltzer et al. (1996) studied 254 siblings (mean age = 10.65 years, ranging from 5 to 17 years old) from 179 families with a child diagnosed with cancer. The researchers examined the overall health status, healthcare utilization, somatization, and health-risk behaviors of the healthy siblings compared to these factors in matched controls or normative data. The instruments and questionnaires utilized in this study included: (a) the National Health Survey Data (1988; as cited in Zeltzer et al., 1996); (b) a 12-item symptom (stomachache, sore throat, hurt all over, stiff neck/back, headache, vomiting, appetite loss, overtired, pain in chest, lump in stomach, blood in urine or bowel movement, and nervousness) checklist that asked if any of these symptoms were present in the last 12 months, using the ratings not at all, sometimes, often, or very often; (c) the Child Behavior Checklist (CBCL), administered to the parents (Achenbach & Edelbrock, 1983; as cited in Zeltzer et al., 1996); (d) the Youth Self-Report (YSR) for children ages 12 to 16 years (Achenbach & Edelbrock, 1987; as cited in Zeltzer et al., 1996); (e) the Family Relations Scale which assesses family support, conflict, and emotional expressiveness and has a Cronbach alpha estimate of internal consistency of .87 (Barbarin, 1994); (f) study-developed instruments such as structured interviews and the Feelings and Attitudes Questionnaire (Carpenter & Sahler, 1991; as cited in Zeltzer et al., 1996); and (g) a physician questionnaire was sent to the healthy sibling's primary care physician to obtain health-related data.

The data from this study indicated that siblings were found to be moderately healthy, although significantly less healthy when comparing reports from their parents with those of parents of matched controls, t (248) = 2.26, $p < .03$. In fact, siblings themselves rated their "present health" as "good" or "excellent" less often than did controls, t (248) = 2.80, $p < .001$. Specifically, siblings reported more "trouble sleeping," t (248) = 2.81, $p < 0.005$, and more "eating problems," t (248) = 2.40, $p < 0.02$, than did controls. Healthcare utilization was surprisingly reduced for these siblings. The parents of these siblings are less likely to seek medical help for a variety of conditions for which parents of control children would bring their children to a doctor. Chi-squares were used for comparison between expected and observed frequencies. Those symptoms with the largest discrepancies between parents of siblings and parents of controls were stomachache (25% vs. 51%, $p < .001$); appetite loss (50% vs. 66%, $p < .001$); hurting all over (66% vs. 82%, $p < .001$); stiff neck/back (71% vs. 85%, $p < .001$); nervousness (60% vs. 72%, $p < .004$); and, pain in chest (2% vs. 97%, $p < .05$). Somatization was found to be the health domain most affected for siblings of children with cancer. When using ANOVAs with post-hoc analyses (Scheffé test) of differences between groups, Zeltzer et al. (1996) found that both males and females of all age groups had scores on the somatic subscale of the CBCL (parent report) and the YSR form (adolescent self-ratings) that were significantly higher than the nonclinical normative scores for those scales, yet lower than the scores of clinical normative samples. The exception was younger boys (6 to 11 years old), whose parents reported somatization similar to that in clinical samples, and adolescent boys, whose self-reports of somatization did not differ from those of the clinical norms.

When comparing the siblings', parents', and physicians' views of the siblings' (a) health status, (b) healthcare utilization, and (c) somatization, parent and sibling ratings were in the same general direction (97% vs. 90% rated as excellent) and physician ratings were very good or excellent in 82% of the cases. As for the parent- and sibling-rated somatic scales (CBCL and YSR), the correlation was positive, in the moderate range, and significant, $r = .35$, $p < .001$. A pattern emerged of parental underreporting of sibling health variables when compared to what the siblings themselves reported, especially in the domain of physical symptoms. Using two-tailed t tests, on the 12-item symptom checklist, parents underrated the total number and intensity of their child's somatic symptoms, as compared to the siblings self report, $t(248) = -12.15$, $p < .001$ and $t(248) = -11.50$, $p < .001$, respectively.

In looking at the major predictors of siblings' (a) health status, (b) somatic complaints, and (c) health risk behaviors, Zeltzer et al. (1996) used three predictor groups (demographic, medical, and family variables) as well as the sibling outcome variables in a hierarchical stepwise multiple regression. The family variables included parental "well-being," somatic symptoms, health status, parent's own healthcare utilization, and family support/expressiveness/conflict. This study used these variables because they deemed them the most responsive to intervention if needed. Every outcome variable matched with its predictor variable was significant at the $p < .05$ level. The data indicated that family conflict predicted physician reporting of sibling health status $F = 13.59$, Adjusted $R^2 = .13$, $p < .001$. Siblings in families with high socioeconomic status utilized healthcare services most often, $F = 20.43$, Adjusted $R^2 = .32$, $p < .001$. In general,

mothers' negative health status and parents' reporting somatic symptoms predicted sibling somatization, $F = 24.75$, Adjusted $R^2 = .27$, $p < .001$.

Additionally, the healthy siblings were interviewed regarding their feeling and attitudes about the sibling diagnosed with cancer. The four subscales derived from the interviews were (a) Interpersonal Problems, (b) Intrapersonal Problems, (c) Fear of Diseases, and (d) Communication. These four factor scores were analyzed in relation to sibling somatization. There were significant correlations between the sibling-reported somatic measures and positive responses to the questions. These researchers found that higher levels of sibling-reported somatic symptoms were associated with higher levels of sibling-reported interpersonal and intrapersonal adjustment difficulties (Youth Self-Report; $r = .41$; Sibling-Reported Symptoms; $r = .35$, $p < .0001$). For instance, those siblings who feared their sibling's cancer would be those siblings who might internalize their negative feelings (e.g., frustration, anger, fear) and thus have more physical symptoms.

The results of the Zeltzer et al. (1996) study suggest that siblings of a chronically ill child are reasonably healthy, but the parents of these children are less inclined to pursue medical help for a variety of conditions compared to those parents in the control group. Somatization was the health area most affected for the healthy siblings. They reported significantly more symptoms and with significantly greater severity than did their parents when asked about the somatic status of their healthy children. This difference may be because the healthy siblings' symptoms may pale in comparison to the ill child's symptoms. This hypothesis was supported by the siblings' feeling that no one cares about them and their physical symptoms. Children usually turn to their parents for

support, nurturing, and guidance in attempts to feel better when they feel sick. However, as this study found, if their parents are already not feeling well themselves and have their own physical symptoms to worry about, in addition to caring for and worrying about their child with cancer, little energy may remain for the rest of the children.

In summary, the physical health of siblings of a chronically ill child were found to be adequate, but they were found to be less healthy when compared to reports from parents of the matched control group. These siblings were likely to have sleeping difficulties, stomachaches, and eating problems. In addition, siblings in the cancer group were found to have more somatic complaints. Furthermore, parents of siblings in the cancer group were more likely to underreport physical symptoms that the siblings themselves found to be distressful. This may be due to the severity of problems the cancer child was experiencing compared to those physical problems of the healthy siblings. These parents may be less able to detect problems in their healthy children unless they notice something very unusual. Finally, the healthy siblings who had more interpersonal and intrapersonal adjustment difficulties also had more somatic symptoms. This may indicate that, when the healthy siblings experience more adjustment difficulties, the likelihood of somatic or physical problems increases.

Adaptation

In three separate studies (Sahler et al., 1994; Sargent et al., 1995; Zeltzer et al., 1996) using the same database, researchers were interested in looking at the levels of sibling adaptation to childhood cancer. In particular, they wanted to determine which siblings demonstrated an ability to cope with the stressful circumstance of childhood cancer in such a way that they returned to a level of adaptation that was similar to or

possibly exceeded that existing before the stress. This capacity has been specified as resiliency, the tendency to "rebound." To examine the differences between the children who are psychosocially resilient and those who become dysfunctional in the face of childhood cancer, the researchers categorized the siblings (N = 238) into four groups, based on level of adaptation: Dysfunctional (n = 51, 22%), Intermediate 1 (n = 30, 30%), Intermediate 2 (n = 80, 34%), and Resilient (n = 77, 32%).

For the most part all the siblings in the dysfunctional group had problems before and after the diagnosis that often required psychological treatment. Siblings in the Intermediate Group 1 had problems before diagnosis, which remained stable or improved. They also had problems which developed after diagnosis, but which did not appear to require treatment. In the Intermediate Group 2, the siblings had problems that developed after the diagnosis, but did not require treatment. In the Resilient group, about a quarter of the siblings had problems before diagnosis, but no problems developed after the diagnosis, and they did not need treatment. Analysis of the demographic distribution of siblings among the four adaptational groups revealed no significant differences except for socioeconomic status (siblings in higher socioeconomic groups were more likely to be resilient), which was marginally significant at the $p < .05$ level.

When comparing levels of sibling adaptation to childhood cancer, a major risk factor for the development of problems after diagnosis is the presence of problems before diagnosis (Sahler et al., 1994), a finding in keeping with Kazak's (1989) that siblings with a more problematic level of adjustment (due to family, personal, or societal factors) before the illness are likely to have an increased incidence of problems after diagnosis. Of those in the Dysfunctional group (n = 51), 95% (48) had preexisting problems of some

type. Of the 77 siblings in the Resilient group, 73% (56) had no problems before diagnosis. The incidence of problems reported both before and after diagnosis appears unreasonably high, given that the incidence of prediagnosis problems was found to be only 7.7% when information from the national survey questions was used. Of those siblings with new-onset problems for which treatment was neither sought nor even apparently considered, the researchers found that 40% (39) of the 99 siblings with preexisting problems developed problems of significance requiring psychological care. All of these siblings were in the Dysfunctional group. However, only 2% (3) of the 139 siblings without such prior problems developed problems after diagnosis that required psychological care. This between-group (prior vs. no prior problems) difference in the prevalence of new-onset problems requiring treatment is highly significant, $p < .001$.

The definition of the four levels of adaptation as determined from parent interviews was independently validated by the Behavior Problem Index scores that showed expected differences among the groups when compared to the general population. The finding of an extremely wide irregularity in sibling response helped to explain the substantial inconsistencies noted to date from studies that reported the presence or absence of problems as distinct outcomes rather than a part of a continuum of adaptation (Sahler et al., 1994).

In the Sargent et al. (1995) study, many siblings reported positive effects of cancer in the family. To ascertain if reporting of positive outcomes was predictive of the four adjustment groups, a "positive perception" subgroup of siblings was distinguished based on responses to the interview questions. Of the 41 siblings who reported becoming more compassionate, 42% reported also becoming closer to family members and 71%

reported some positive outcome. Of those siblings (n = 40) who reported that their families became closer, 73% reported a positive outcome. The data suggested that if a sibling noted one positive effect of cancer in the family, then it was more likely that additional positive effects would be experienced. Analysis of the variance of the number of positive effects reported by siblings and the adaptation group revealed no significant differences, $F(3,234) = 0.98$, ns. There was a strong association between age group and positive perception. Older siblings who became more compassionate or caring because a sibling had cancer were far more likely to have reported positive effects of cancer in the family, $F(1, 252) = 78.21$, $p < .001$. The lack of a strong relationship between siblings' responses and level of adaptation was disappointing to Sargent et al. (1995). The lack of a relationship suggests that the selected siblings' expressions of feelings and thoughts is a poor predicator of those at potential risk or those likely to be immune to problems.

A system was used to classify the healthy siblings according to three levels of emotional/behavioral adaptability (resilient, intermediate, and dysfunctional). Zeltzer et al. (1996) wanted to see if there was a difference in the three levels of adaptability as experienced by siblings having a sibling with cancer. In the Zeltzer et al. study, the number of siblings in the three adaptability levels were Resilient (n = 77), Intermediate (n = 110), and Dysfunctional (n = 51). In a series of analyses, Zeltzer et al. attempted to determine if these emotional/behavioral adaptability groups were also related to health outcomes. One-way ANOVAs were performed on each of the major outcome variables in the health domains to test for differences across the three adaptability groups. The data revealed that, in almost every health outcome domain, the Resilient and Dysfunctional groups significantly differed from each other, most notably on the CBCL somatic scale

(Dysfunctional = 2.61, Resilient = .81, $F = 12.04$, $p < .001$), parent reported sibling symptoms (Dysfunctional = 1.33, Resilient = .51, $F = 7.13$, $p < .001$), and sibling reports of sibling symptoms (Dysfunctional = 22.08, Resilient = 18.84, $F = 8.90$, $p < .001$). Thus, it appears that health outcomes differ depending upon sibling emotional/behavioral adaptation to the changes brought about by their sick sibling's cancer diagnosis and treatment.

The research data presented on siblings' adaptation to a survivor of childhood cancer is not definitively positive or negative. The research indicated that some siblings seem to become resilient, whereas others become dysfunctional. The range of functioning in siblings with a survivor of childhood cancer is very broad. One leading factor that increases the likelihood of problems after diagnosis is the presence of problems before the diagnosis. Those who became dysfunctional were more likely to need therapeutic interventions to adapt to this stressor, whereas resilient or siblings without prior problems did not need psychological care. Furthermore, the research indicated that if a sibling noted one positive effect from the cancer experience, additional positive effects were also found. For the most part, older siblings were more likely to be compassionate and caring because a sibling had cancer, which suggested that older siblings are more inclined to report positive effects in the family.

Interventions

With the increasing knowledge about how siblings of a survivor of childhood cancer cope, adapt, and adjust to this stressor over time, it is perhaps most important to see what interventions can assist in preventing and/or intervening with siblings who have

emotional, behavioral, and psychological problems. The most productive strategy for identifying coping and adaptive processes and designing relevant interventions will rest on the identification of variables that predict adjustment of siblings, as well as on the identification of specific characteristics of different types of cancer that contribute to increased stress for the sibling (Kazak, 1989). These interventions may help promote healthier coping, adapting, and adjusting to this long-term stressor that has challenged the stability and functioning of the siblings.

The research can help to reliably identify low, moderate, and high-risk groups of siblings and gear different interventions for these groups. Given the age of the siblings, parents constitute a major influence in their lives as well. Therefore, it is essential to involve the parents in any type of prevention or intervention process on the sibling level to cope, adapt, and adjust to the sibling surviving from cancer. Part of an intervention or prevention strategy is to determine (a) the history of illnesses in the family, (b) how the family has coped, (c) how the family has adjusted, (d) how the experience of having a child with cancer relates to preexisting family problems, and (e) what existing sources of emotional and social support the family has (Carpenter & Levant, 1994). This would be invaluable information as to how the family, especially the parents, would assist the siblings' coping and adapting to the childhood cancer survivor.

Adapting and Adjusting

Horwitz and Kazak (1990) found that families' adaptability level may change drastically as the siblings and parents adjust to the ill child's survival from cancer. In trying to care for all the members in the family, some families may necessarily become more flexible, whereas others may impose more structure than usual as a way to adapt to

the challenges (Horwitz & Kazak, 1990; Kazak & Meadows, 1989; Lobato et al., 1988; Perrin, Ayoub, & Willett, 1993). Furthermore, families that are more involved tend to have the siblings' needs and concerns more readily addressed, which assists parents in being more aware of potential problems. Those families who participate regularly in outside social and recreational activities and minimize internal conflict seem to adjust better to the stressor (Perrin et al., 1993). In contrast, siblings who are less well-adjusted have less cohesion, more disorganization, more social isolation, more conflict, more rigid family environments, and are at moderate to high risk for interventions.

In analyzing the relationship between maternal well-being and resource utilization with sibling adaptation, Sahler et al. (1994) found that there is an association between these maternal variables and sibling functioning; that is, mothers who have a lower sense of well-being and who are less satisfied with the support they receive have children who adapt less well. Interventions that assist in fostering a better sense of functioning and providing the level of support the mother needs may be successful in helping siblings adapt better (Kazak & Nachman, 1991; Kazak et al., 1997; Sahler et al., 1994; Speechley & Noh, 1992).

Family communication styles have been identified as another coping mechanism that impacts siblings' adjustment. An open communication style, one in which information is shared, emotions are expressed, and appropriate psychological defenses are employed, has been identified as beneficial for siblings (Brett, 1988; Gallo, Breitmayer, Knafl, & Zoller, 1992). An approach for parents to develop in becoming more effective communicators and listeners is the reflective parenting approach (Gallo, 1988). Within this approach, the most important task for the parents to promote is the

establishment of a good self-concept. Feelings of being accepted, wanted, and capable develop when parents express positive feelings to their children in the years when self-concept is forming. Parents should learn to demonstrate acceptance of the well siblings' concerns and feelings so that the children can better accept their feelings and eventually learn to express them openly. Gallo indicated that some areas of concern expressed by well siblings included (a) their own health, (b) unfairness, (c) negative feelings toward the ill sibling, (d) their own future and that of their ill sibling, and (e) responsibility for sibling and parents.

In reference to those siblings with previously existing problems, the results of the Sahler et al. (1994) study suggested that they are at a higher risk for developing emotional/behavioral problems requiring intervention. As a preventative measure, Sahler et al. (1994) suggested several intervention strategies that may assist in facilitating sibling adaptation, including (a) strategies for the effective disclosure of age-appropriate information to the healthy siblings about the cancer diagnosis and treatment, (b) strategies for allowing the sibling to participate in the ill sibling's treatment and care, and (c) strategies for minimizing siblings' emotional isolation from their parents.

In a study of 265 members from 118 families that had a childhood survivor of cancer, Spilka, Zwartjes, and Zwartjes (1991) found that religion positively correlated with parental perceptions of good patient-sibling and parent-healthy-sibling relationships for both prediagnosis and survival. Their findings supported the assumption that more religious families appear closer under both normal and crisis conditions. With the growing importance of religion following diagnosis and beyond, these connections increased in strength for parents and siblings. Religion could thus act as a protective

system that motivates efforts to cope actively and constructively with a survivor of childhood cancer. VanDongen-Melman et al. (1995) found that religious belief and practice were associated with fewer problems in the family because religious affiliation might be associated with greater social support and strengthening intrapersonal characteristics. Finally, religion might provide extra strategies to cope with a survivor of cancer.

Therefore, the research findings indicated that effective adapting and adjusting are aided by the family's ability to tend to the siblings' needs and concerns as well as participate in extracurricular activities. Interventions that assist the mothers' level of support can help siblings adapt more readily. In addition, an open family communication pattern fosters emotional candidness and the exchange of information in an honest manner. When parents exhibit an acceptance of the healthy siblings' feelings, the siblings then are better able to accept their own feelings and know that their concerns are heard. Religion and religious practice of the family was also found to be a protective factor for siblings' adaptation and adjustment. Religious affiliation can provide greater social support and strength to assist the siblings. For those siblings at high risk for developing emotional/behavioral problems, the research indicated that disclosing age-appropriate information, participating in the ill child's care, and minimizing emotional isolation from their parents can provide the needed buffer to help these siblings adapt and adjust to the cancer experience.

Coping

Coping is one mechanism that can assist in reducing the impact of demands of the cancer experience on siblings. In fact, coping can include a combination of several

approaches that assist in reducing the number and/or intensity of demands, including (a) acquiring additional resources, (b) maintaining or strengthening present resources, and (c) reframing the situation to make it more tolerable (Baum & Baum, 1989). Before intervening, one must realize that siblings have coping skills. Most children develop age-appropriate coping skills before their sibling is diagnosed and do not lose them. The siblings need ongoing support of these skills.

Barbarin, Hughes, and Chelser (1985) looked at coping strategies in parents of children with cancer. They discovered eight coping strategies that were effective in assisting parents, which could help assist the healthy siblings' coping with the survival of their sibling from childhood cancer. These coping strategies were grouped as "problem focused," which included (a) information seeking, (b) problem solving, and (c) help seeking and "emotional focused," which included (a) acceptance, (b) optimism, (c) maintenance of emotional balance, (d) denial, and (e) religion. In using these strategies, the parents may help prevent problems in the future or assist in intervening when emotional, behavioral, and/or psychological problems begin to arise. Some other techniques that parents can use to help the healthy siblings cope with the family stressor of childhood cancer include the following: (a) share feelings with children, thereby making it easier for the child to express his or her own feelings, (b) include siblings, as much as possible, in family decisions, (c) acknowledge siblings' desire and efforts to take on additional responsibilities in the family, (d) maintain a positive outlook, (e) alert teachers to the family situation and encourage feedback, (f) maintain a practical balance of attention among all the children in the family, enhancing a sense of control and increased confidence in living with the demands of having a surviving sibling, (g) assign

meaning to the experience of the childhood cancer, and (h) call upon significant relatives, friends, and parents of friends to spend time with the healthy siblings to help them feel cared about (Brett, 1988; Carpenter & Levant, 1994; Martinson et al., 1990). The major goal is to keep the siblings interacting in as normal a manner as possible.

Research appears to support the fact that coping strategies are another intervention that can reduce the effects of the cancer experience on the siblings. Before deciding what coping strategies siblings may need, parents and mental health providers should realize that these siblings already have coping strategies. Further strengthening of these skills is imperative, along with provision of additional strategies. In addition, these strategies can be problematically or emotionally focused.

Healthcare

Although only 18% (43) of physicians reported that siblings had less than very good or excellent health in the study conducted by Zeltzer et al. (1996), it was reported that siblings' physicians saw these children less often compared to a matched sample of "healthy children." Regardless of the reason for the visit, there should be an opportunity for the sibling to talk alone with the physician to explore physical and emotional well-being, especially feelings about the cancer experience and its effect on the family and siblings. In addition, the parents' own health and well-being should be addressed, because parental health status affects sibling health outcome (Zeltzer et al., 1996). It is important for physicians and their staff to remind the parents to take care of themselves as well and to help them devise appropriate strategies for doing so. In taking care of themselves, parents may be able to provide more support for the otherwise relatively neglected siblings. There is a need for more systematic physical and emotional

evaluation as part of routine health care or of care provided in response to specific, especially recurrent symptoms, which may be serving as a cry for help.

Support Groups

Some implications from the Derouin and Jesse (1996) study was that support groups may be especially useful in helping siblings gain new knowledge and share experiences and feelings with siblings in similar situations. Peer support groups also can serve as a forum for discussion of many issues. Recurrent themes in support groups for siblings of children with cancer included (a) the special attention given to the ill child, (b) lack of control over child care arrangements, (c) isolation, (d) worry about the cause of cancer and becoming ill themselves, (e) awareness of the differences in the ill child's life, (f) guilt over not being ill, and (g) lack of information regarding the illness (Sargent et al., 1995). In addition, older siblings who have learned to cope positively and adapt may be good support resources for children who recently have learned that a sibling has a chronic illness.

Support groups for parents are an appropriate intervention to help their healthy children and themselves cope and adapt to the surviving sibling. Parental support groups are likely to foster a sense of mastery and coping skills through (a) the dissemination of information, (b) the opportunity to ventilate emotional distress, and (c) the ability to become reoriented toward identifying problems and generating ideas (Overhosler & Fritz, 1990; Speechley & Noh, 1992). Gallo (1988) stated that support groups can assist the parents in understanding how development and temperament, past coping experiences, and present environment affect their children's coping strength. Groups can also help parents to understand what types of responses, both positive and negative, they might

expect from their healthy siblings, given that another sibling had been diagnosed with cancer. Parents may often expect more from the well child than the child is capable of at the time. If developmental needs of specific age groups are addressed, the potential for the well child to feel neglected, resentful, and isolated might be reduced (Gallo, 1988). Therefore, support groups for siblings and parents are a useful intervention in that they provide a forum for information to be exchanged, new knowledge disseminated, feelings and concerns to be heard, and for fostering a sense that they are not alone.

Discussion and Conclusions

The literature reviewed in this paper has shown that having a sibling surviving childhood cancer has a profound impact on the healthy siblings' ability to cope, adjust, and adapt. The research indicated that siblings' ability to cope, adapt, and adjust to another sibling surviving childhood cancer is not conclusively positive or negative. The range of functioning of siblings is rather widespread. However, siblings having no adjustment problems prior to or following the diagnosis of cancer ranged from two fifths to one half of the sample population. Therefore a large percentage of siblings do not have adjustment problems needing psychological care. The siblings' responses to the cancer of another sibling will depend on a variety of factors such as: (a) the age of the siblings, (b) the cognitive stage of development of the siblings, (c) the age of the ill sibling, (d) the relationship between the ill sibling and the healthy siblings, (e) the family structure, (f) family coping patterns, (g) family adaptation ability and dynamics, (h) the family response to the cancer, (i) the langauge used to discuss the cancer, and (j) the disruptions caused by the cancer (Ross-Alaolmolki, Heinzer, Howard, & Marszal, 1995).

The research data indicated that there is no one-to-one correspondence between the presence of problems in siblings and the presence of childhood cancer in the family. This further emphasizes the idea that there is no straightforward, simple, or linear relationship between the siblings' ability to cope, adapt, and adjust and any of the many sibling characteristics.

For some siblings, the cancer experience allowed them to rise above this stressor and become more compassionate and empathetic and to have a greater appreciation for their lives. Some siblings appear to be more resilient or to adapt better. One plausible explanation could be that being with and watching another sibling go through the treatment, as well as the side effects of fighting cancer, may force the healthy siblings to reorder their priorities. In this manner, these siblings may even develop more prosocial behaviors, have a healthy respect for life, and establish positive self-esteem. For others, this cancer experience is an untimely event that alters the family system in such a way that the siblings have more difficulty and a number of them need mental health services to deal with their emotional, behavioral, and/or psychological problems. There seems to be a myriad of factors that lead to varied outcomes in the well siblings' functioning. These outcomes seem to be dependent on (a) the specific features of the cancer, (b) the parents' and siblings' coping patterns, (c) the family communication style, (d) the developmental level of the siblings, (e) the stage of the family life cycle, and/or (f) the level of social support available to the family members.

A majority of the literature reviewed indicated that, as a whole, siblings of a survivor of childhood cancer do experience elevated emotional and behavioral problems when compared to children in general. Yet, these siblings did not exhibit more problems

in overall psychological adjustment than did siblings from "healthy families." The research data suggested that there are some subgroups of siblings at particular risk for having problems. Younger boys (ages 4 to 11 years) seem to be the most vulnerable to problems. This may be due to developmental factors including boys' psychosocial and expressive childishness compared to girls of the same age. Additionally, two other predictor variables for the presence or absence of problems emerging after diagnosis appear to be the compound variable gender/age and the presence of problems existing before diagnosis (Sahler et al., 1994).

Although siblings demonstrated that they could adjust to the survival of a sibling with cancer, the literature showed that siblings had to cope with both positive and negative effects. On the negative side, siblings reported concerns with (a) family separations, (b) lack of attention given to them, (c) negative feelings in themselves and about other family members, and (d) physical, mental, and emotional changes in the ill sibling due to adverse side effects from treatments. On the positive side, siblings reported that (a) they became more compassionate and caring, (b) the family became closer, and (c) they felt helpful to their brother/sister and the family. Furthermore, siblings greater than 12 years of age often were better able to cope more effectively and describe positive effects of the cancer experience than younger siblings were. Developmenta ly, older siblings may be better at rising above the stress of the cancer, are able to verbalize their feelings both positive and negative about this cancer experience, have more strategies and resources for coping, and have support from outside activities, all of which can act as a defense against the effects of the cancer experience. However, young siblings were able to be empathic to the sibling with cancer.

The need for the healthy siblings to be able to maintain communication with their families to express their feelings, to receive age-appropriate information about cancer and the treatment, and to be active participants in the ill sibling's care was reported to assist in their ability to cope. Without the benefit of unambiguous and age-appropriate information about the complexity of the ill sibling's treatment, healthy siblings were found to rely on their own interpretations. This often yielded a distorted picture of fear and anxiety about what would happen to the family and the healthy siblings' role within the family system.

Looking at physical health and well-being, research indicates that siblings of childhood cancer survivors are fairly healthy; but their parents did not access healthcare for various conditions as frequently as did those parents of healthy children. Somatization was the health area most affected for the healthy siblings, but their rating of scores on behavior checklists was lower than clinical normative samples. There is a need to do future research on how others, such as physicians or other health professionals, can assist these siblings in receiving the healthcare they need, if their parents have their own physical problems and worries about the ill sibling surviving cancer.

When levels of adaptation for siblings were used in the research, the data suggested that a principal risk factor for the development of problems after a sibling is diagnosed with cancer is the presence of problems before diagnosis. The research showed that there was a large within-group difference among those with preexisting problems needing some type of mental health services compared to those without preexisting problems. Those who became dysfunctional were more likely to need therapeutic interventions to adapt to this stressor, whereas resilient siblings without prior

problems did not need psychological care. However, when looking at positive effects of the cancer in the family, the level of adaptation of the siblings had no barrier on their positive perception. The data revealed that if siblings, generally older than 12 years of age, stated a positive effect they were more apt to perceive additional positive effects. In addition, when physical health and well-being were considered, the resilient and dysfunctional groups differed significantly from each other. This indicated that the siblings' health differed substantially depending on the siblings' emotional/behavioral adaptation level.

Interventions can be preventative or intervening for the healthy siblings in order to assist in their ability to cope, adapt, and adjust to the sibling's surviving from childhood cancer. Specifically, intervention can be used to help prevent, limit, or eliminate emotional, behavioral, and/or psychological problems. In addition to particular interventions used, it is essential to gather information concerning (a) the family's history of illnesses, (b) how the family has coped, (c) whether the family adapted or not, (d) how the child's cancer diagnosis and treatment related to previous family problems, and (e) the extent of the family's emotional and social support system.

Intervening factors that increase the siblings' ability to adapt and adjust include (a) cohesive and adaptable families, (b) participation in outside social and recreational activities, (c) reduced internal conflicts, (d) support for mothers, and (e) religion and religious practice or affiliation. Gaining additional coping strategies is also beneficial. It is important to remember that siblings already have existing and developmentally appropriate coping strategies. They need reinforcement of those strategies as well as new coping mechanisms, which could be problematically or emotionally focused. One

important coping strategy is to keep all the siblings interacting with each other as normally as possible, which is advantageous to the siblings' mental health. Healthcare maintenance is another key intervention strategy. The healthy siblings tend to be seen less often by physicians. Therefore, at each visit it is crucial for the medical staff to provide a thorough physical and emotional evaluation as part of routine health care or care provided in response to specific and/or recurrent symptoms.

Support groups for both siblings and parents can be extremely useful. These groups can provide a level of emotional support that other interventions cannot. Groups can be an avenue to (a) exchange information, (b) disseminate knowledge about the illness and what the type of reactions seen, (c) help in detecting problems in family members and generating ideas, (d) share experiences and feelings, and (e) foster a sense of hope and ability to see beyond the cancer experience.

Directions for Future Research

It seems that the chronic-crisis paradigm in research of siblings of a childhood cancer survivor has shifted from a negative, deficit, and psychopathological view to viewing childhood cancer as a stressor. This approach enables researchers to integrate more concepts such as family strengths, coping, competence, resilience, self-regulation, and well-being (Ross-Alaolmolki et al., 1995). Although there has been an expansion in the past 10 years in the research on siblings' adaptation and coping to a survivor of childhood cancer, there are a number of areas needing further study.

Many of the studies that have been conducted are single-site studies employing small, heterogeneous samples, with only a few being multi-site studies from diverse

geographic, demographic, ethnic, and socioeconomic populations of the United States. Consequently, additional studies with larger and more generalizable samples are needed to replicate and enhance current findings regarding siblings' coping and adaptation. In addition, another avenue to explore is a short-term longitudinal study in which the siblings' developmental changes can be considered, as well as the nature of change and/or stability of their coping and adjustment over a brief period of time (Armstrong, 1995). It would also be beneficial to conduct studies using multiple investigators and center collaboration in order to obtain large enough and relatively homogenous sample sizes of specific subgroups of cancer diagnoses. In this manner, the investigators could gain valuable information in the prognosis and treatment of specific types of cancer and how they can have distinct effects on siblings' coping and adaptation. In addition, there needs to be more research addressing the relationship between risk and resistance factors in siblings.

There is urgent need to have fathers more involved in the research. Overall, fathers rarely participate in this type of research. Their information concerning the siblings' functioning is lacking and would add another perspective, besides the mother's, as to how the healthy siblings are coping, adapting, and adjusting. The mother was often the only parent reporting how the siblings were functioning. Using parents to rate the coping and adaptive level of their healthy children is acceptable, yet they usually base their evaluations on externalized behavior. A much more powerful research venue would be to have the siblings' own perceptions through direct psychological testing, which would provide researchers with insight into the internalized feeling that only the siblings

can report. Furthermore, it may be appropriate to assess siblings' adjustment and coping from sources external to the family, including health care teams and school officials.

Future research would also benefit from looking at sibling adaptation and coping from an age/developmental perspective. Most often, the research to date involved broad age ranges with no particular developmental age being targeted. Studies could be designed to specifically target preschool, elementary, and high school siblings in order to address developmental differences in adjustment. By targeting particular developmental age groups, the researchers could more accurately determine and categorize the specific strengths and weaknesses toward adaptation that are apparent for the siblings within each specific developmental age group. The effect of the illness on the siblings when an adolescent, as compared to an infant, has cancer has much bearing on how the siblings are able to adapt and cope. Because siblings at different developmental stages perceive sibling functioning differently, it is important to consider whether the different measures of adjustment are necessary at different stages or whether interpretation of data should be varied by developmental factors. Additionally, research could assist in defining more clearly which siblings in the family, older or younger, may have more problematic behavior or difficulty dealing with another sibling diagnosed with cancer.

Another area research should focus on is incorporating standardized tests and measures, including those that have been used before in cancer research and illness-specific measures. Currently, there are not many illness-specific measures of family functioning (Drotar, 1997). These types of measures would focus on general factors of family functioning such as perceived conflict or support, problem solving, cohesiveness, and stress tolerance, rather than specific behavioral or emotional problems. There needs

to be more identification of measures of sibling and family coping, which proactively helps professionals learn about coping strategies (Kazak et al., 1994). It is important to know whether having a survivor of childhood cancer is associated with psychopathology in family members. Existing data indicated that it is not for the majority of families. However, measures of psychopathology do not address coping and adjustment, and a lack of pathology should not be accepted as evidence of good coping or adjustment. Measures of coping and adjustment are numerous and often geared toward particular populations. Coping and adaptation are much more diverse than pathology and are an area in which a greater research emphasis is needed.

Because children will continue to get cancer and siblings will need to learn to cope, adapt, and adjust to the disease, ongoing research is a necessity. Conducting good family research on siblings is difficult, and many of the theoretical and methodological issues involved are exceedingly complex. Although individual studies have their limitations, when taken together they seem to draw significant and similar conclusions. These siblings' overall psychological and psychosocial functioning is adequate when compared to siblings from non-illness inflicted families. Although future research is needed in these areas, the research to date has laid the foundation for clearer and more thorough understanding of siblings' ability to cope, adapt, and adjust to a childhood survivor of cancer.

REFERENCES

Armstrong, F. D. (1995). Commentary: Childhood cancer. [Special issue: Pediatric chronic conditions.] Journal of Pediatric Psychology, 20, 417-421.

Baum, B. J., & Baum, E. S. (1989). Psychosocial challenges of childhood cancer. Journal of Psychosocial Oncology, 7, 119-129.

Barbarin, O., Hughes, D., & Chelser, M. (1985). Stress, coping, and marital functioning among parents of children with cancer. Journal of Marriage and the Family, 47, 473-480.

Birenbaum, L. K. (1990). Family coping with childhood cancer. The Hospice Journal, 6, 17-33.

Brett, K. M. (1988). Sibling response to chronic childhood disorders: Research perspectives and practice implications. Issues of Comprehensive Pediatric Nursing, 11, 43-57.

Brett, K. M., & Davis, E. M. B. (1988). What does it mean? Sibling and parental appraisals of childhood leukemia. Cancer Nursing, 11, 329-338.

Campbell, T. L. (1993). Impact of family factors on childhood illness. Family Systems Medicine, 11, 433-440.

Carpenter, P. J., & Levant, C. S. (1994). Sibling adaptation to the family crisis of childhood cancer. In D. Bearison, & R. Mulhern (Eds.), Pediatric psychooncology: Psychological perspectives on children with cancer (pp. 122-142). New York: Oxford University Press.

Cohen, D. S., Friedrich, W. N., Jaworski, T. M., Copeland, D., & Pendergrass, T. (1994). Pediatric cancer: Predicting sibling adjustment. Journal of Clinical Psychology, 50, 303-319.

Cook, A. R. (Ed.). (1996). The new cancer sourcebook. Detroit, MI: Omnigraphics.

Daniels, D., Moos, R. H., Billings, A. G., & Miller, T. J. (1987). Psychosocial risk and resistance among children with chronic illness, healthy siblings, and healthy controls. Journal of Abnormal Child Psychology, 15, 295-308.

Derouin, D., & Jessee, P. O. (1996). Impact of a chronic illness in childhood: Siblings' perceptions. Issues in Comprehensive Pediatric Nursing, 19, 135-147.

Drotar, D. (1994). Psychological research with pediatric conditions: If we specialize, can we generalize? Journal of Pediatric Psychology, 19, 403-414.

Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? Journal of Pediatric Psychology, 22, 149-166.

Drotar, D., & Crawford, P. (1985). Psychological adaptation of siblings of chronically ill children: Research and practice implications. Journal of Developmental and Behavioral Pediatrics, 6, 355-362.

Evans, C. A., Stevens, M., Cushway, D., Houghton, J. (1992). Sibling response to childhood cancer: A new approach. Child Care, Health and Development, 18, 229-244.

Gallo, A. M. (1988). The special sibling relationship in chronic illness and disability: Parental communication with well siblings. Holistic Nursing Practice, 2, 28-37.

Gallo, A., Breitmayer, B., Knafl, K., & Zoller, L. (1992). Well siblings of children with chronic illness: Parents' reports of their psychological adjustment. Pediatric Nursing, 18, 23-27.

Hamlett, K. W., Pelligrini, D. S., & Katz, K. S. (1992). Childhood chronic illness as a family stressor. Journal of Pediatric Psychology, 17, 33-47.

Horwitz, W. A., & Kazak, A. E. (1990). Family adaptation to childhood cancer: Sibling and family systems variables. Journal of Clinical Child Psychology, 19, 221-228.

Kazak, A. E. (1989). Families of chronically ill children: A systems and social-ecological model of adaptation and challenge. Journal of Consulting and Clinical Psychology, 57, 25-30.

Kazak, A. E., Barakat, L. P., Meeske, K., Christakis, D., Meadows, A. T., Casey, R., Penati, B., & Stuber, M. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. Journal of Consulting and Clinical Psychology, 65, 120-129.

Kazak, A. E., Christakis, D., Alderfer, M., & Coiro, M. J. (1994). Young adolescent cancer survivors and their parents: Adjustments, learning problems, and gender. Journal of Family Psychology, 8, 74-84.

Kazak, A. E., & Meadows, A. T. (1989). Families of young adolescents who have survived cancer: Social-emotional adjustment, adaptability, and social support. Journal of Pediatric Psychology, 14, 175-191.

Kazak, A. E., & Nachman, G. S. (1991). Family research on childhood chronic illness: Pediatric oncology as an example. Journal of Family Psychology, 4, 462-483.

Kotchick, B. A., Forehand, R., Armistead, L., Klien, K., & Wierson, M. (1996). Coping with illness: Interrelationships across family members and predictors of psychological adjustment. Journal of Family Psychology, 10, 358-370.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Leonard, B. J. (1991). Siblings of chronically ill children: A question of vulnerability versus resilience. Pediatric Annals, 20, 501-506.

Lewis, F. M., Hammond, M. A., & Woods, N. F. (1993). The family's functioning with newly diagnosed breast cancer in the mother: The development of an explanatory model. Journal of Behavioral Medicine, 16, 351-370.

Lobato, D., Faust, D., & Spirito, A. (1988). Examining the effects of chronic disease and disability on children's sibling relationships. Journal of Pediatric Psychology, 13, 389-407.

Martinson, I., Gilliss, C., Colaizzo, D. C., Freeman, M., & Bossert, E. (1990). Impact of childhood cancer on healthy school-age siblings. Cancer Nursing, 13, 183-190.

Overholser, J. C., & Fritz, G. K. (1990). The impact of childhood cancer on the family. Journal of Psychosocial Oncology, 8, 71-85.

Perrin, E. C., Ayoub, C. C., & Willett, J. B. (1993). In the eye of the beholder: Family and maternal influences on the perceptions of adjustment of children with a chronic illness. Journal of Developmental and Behavioral Pediatrics, 14, 94-105.

Rait, D. S., Ostroff, J. S., Smith, K., Cella, D. F., Jan, C., & Kesko, L. (1992). Lives in a balance: Perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. Family Process, 31, 383-397.

Ross-Alaolmolki, K., Heinzer, M., Howard, R., & Marszal, S. (1995). Impact of childhood cancer on siblings and family: Family strategies for primary health care. Holistic Nursing Practice, 9, 66-75.

Sahler, O. J., & Carpenter, P. J. (1988). Relationship between family functioning and sibling adaptation to the pediatric cancer experience. Journal of Developmental and Behavioral Pediatrics, 9, 106-107.

Sahler, O. J., & Carpenter, P. J. (1989). Evaluation of a camp program for siblings of children with cancer. American Journal of Diseases of Children, 143, 690-696.

Sahler, O. J., Roghmann, O., Carpenter, P. J., Mulhern, R., Dolgin, M. J., Sargent, J. R., Barbarin, O. A., Copeland, D. R., & Zeltzer, L. K. (1992). Adaptation to childhood cancer: Sibling psychological distress. Pediatric Research, 31, 137-149.

Sahler, O. J., Roghmann, O., Carpenter, P. J., Mulhern, R., Dolgin, M. J., Sargent, J. R., Barbarin, O. A., Copeland, D. R., & Zeltzer, L. K. (1994). Sibling adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptation levels. Journal of Developmental and Behavioral Pediatrics, 15, 353-366.

Sargent, J. R., Sahler, O. J., Roghmann, K. J., Mulhern, R. K., Barbarian, O. A., Carpenter, P. J., Copeland, D. R., Dolgin, M. J., & Zelter, L. K. (1995). Sibling adaptation to childhood cancer collaborative study: Siblings' perceptions of the cancer experience. [Special issue: Pediatric chronic conditions.] Journal of Pediatric Psychology, 20, 151-164.

Speechley, K. N., Noh, S. (1992). Surviving childhood cancer, social support, and parents' psychological adjustment. Journal of Pediatric Psychology, 17, 15-31.

Spilka, B., Zwartjes, W. J., & Zwartjes, G. M. (1991). The role of religion in coping with childhood cancer. Pastoral Psychology, 39, 295-304.

Van Dongen-Melman, J. E. W. M., Pruyn, J. F. A., De-Groot, A., & Koot, H. M. (1995). Late psychosocial consequences for parents of children who survived cancer. Journal of Pediatric Psychology, 20, 567-586.

Walker, C. L. (1988). Stress and coping in siblings of childhood cancer patients. Nursing Research, 37, 208-212.

Walker, C. L. (1990). Siblings of children with cancer. Oncology Nursing Forum, 17, 355-360.

Zeltzer, L., Dolgin, M. J., Sahler, O. J. Z., Roghmann, K., Barbarin, O. A., Carpenter, P. J., Copeland, D. R., Mulhern, R. K., & Sargent, J. R. (1996). Sibling adaptation to childhood cancer collaborative study: Health outcomes of siblings of children with cancer. Medical Pediatric Oncology, 27, 98-107.

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